DOCUMENT RESUME

ED 460 445 EC 306 606

AUTHOR	Levine, Karen
TITLE	Pervasive Developmental Disorders: PDD-NOS, Asperger's Disorder and Autism. Parent Information Booklet.
INSTITUTION	Children's Hospital, Boston, MA. Inst. for Community Inclusion.
PUB DATE	1994-11-00
NOTE	34p.
AVAILABLE FROM	Institute for Community Inclusion/UAP, Developmental Evaluation Center, Children's Hospital, 300 Longwood Ave., Boston, MA 02115. Tel: 617-735-6506; Tel: 617-735-6956 (TDD); Web site: http://www.KiernanW@1.tch.harvard.edu.
PUB TYPE	Guides - Non-Classroom (055)
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	*Asperger Syndrome; Asperger Syndrome; *Autism; Behavior Problems; Children; *Clinical Diagnosis; Communication Skills; Drug Therapy; *Educational Environment; Elementary Secondary Education; *Etiology; Heredity; Intervention; Outcomes of Treatment; Social Development; Special Health Problems; Student Characteristics; *Symptoms (Individual Disorders)
IDENTIFIERS	Rett Syndrome

ABSTRACT

This information booklet is designed for parents who have a child who has been diagnosed with Pervasive Developmental Disorder (PDD) or Asperger's Disorder. It provides information on: (1) the definition of PDD; (2) the five subtypes of PDD, including PDD "not otherwise specified," Asperger's disorder, autistic disorder, childhood disintegrative disorder, and Rett's disorder; (3) general characteristics of children with PDD; (4) the causes of PDD; (5) medical problems of children with PDD or autism, including sensitivity to sound, mild motor problems, sensitivity to certain kinds of touch, and seizures; (6) the unique nature of children with PDD or autism; (7) clinical diagnosis; (8) mental retardation and PDD or autism; (9) heredity of PDD; (10) communication skills of children with PDD or autism; (11) recovery of children with PDD; (12) problem behaviors; (13) choosing the best type of intervention or schools and characteristics of good programs, including structured schedules, fewer children per teacher, emphasis on social and communication development, use of play to promote social and communication development, and use of positive behavior management techniques; (14) drug therapy; and (15) and evaluating new treatments. Information on parent organizations for parents of children with PDD or autism are provided. (CR)

Reproductions supplied by EDRS are the best that can be made
from the original document.

ED 460 445

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

✓ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

Pervasive Developmental Disorders: PDD-NOS, Asperger's Disorder and Autism

Parent Information Booklet

by

Karen Levine, Ph.D.

EC 306606

BEST COPY AVAILABLE

Pervasive Developmental Disorders: PDD-NOS, Asperger's Disorder, and Autism

Parent Information Booklet

Karen Levine, Ph.D.
Director of Psychology
Institute for Community Inclusion/UAP
Developmental Evaluation Center
Children's Hospital
300 Longwood Avenue
Boston, MA 02115

November 1994

The Institute for Community Inclusion, a University Affiliated Program, comprises the Developmental Evaluation Center, the Training and Research Institute for People with Disabilities, and the Center on Promoting Employment: a Rehabilitation and Research Training Center. It is based at Children's Hospital, Boston, with additional offices at the University of Massachusetts at Boston. The Institute is committed to developing resources and supports for people with disabilities and their families that foster independence, productivity, and inclusion in community settings. The Institute carries out its mission through training, technical assistance, research, exemplary clinical, consultative and employment services, and dissemination of publications and materials.

To contact the Institute to obtain additional copies of this booklet (or in an alternate format), or for more information, you may write, phone or e-mail:

Institute for Community Inclusion/UAP
300 Longwood Avenue
Boston, MA 02115

617/735-6506; voice
617/735-6956; TDD
KiernanW@a1.tch.harvard.edu; Internet

What is Pervasive Developmental Disorder ("PDD") and what is Asperger's Disorder?

This information booklet is for parents who have a child who has been diagnosed with "PDD" or Asperger's Disorder. I have written this because, while there is a great deal written about children with autism, it is difficult to find information for parents about these other diagnoses. This information is intended to provide you with general background information about these diagnostic labels, rather than specific knowledge about your child.

PDD and Asperger's Disorder are labels, or diagnoses, to describe a set of observable characteristics and difficulties in children. They should be considered to be "shorthand" descriptions referring to a particular set of difficulties some children have. They are labels in the same sense that "obesity" is a label of a characteristic, not in the sense that, for example, measles describes a certain disease, or Down syndrome describes a certain chromosomal anomaly. These diagnoses are made on the basis of observations, parent interview, and when possible, language and cognitive testing, to assess the child's functioning in the domains of verbal and nonverbal communication, social relatedness, cognition, play and behavior. There is no blood or urine test, nor is there a

chromosomal or neurological test for these diagnoses. These types of tests are often done in the diagnostic process, however, to find out if the child may have some other type of disorder that is causing the autistic behaviors.

The name "Pervasive Developmental Disorder" is very misleading, because many children with PDD do not demonstrate difficulties in all areas of functioning. Children with PDD instead have quite specific areas of difficulty, often with other areas developing more quickly, sometimes as well as, or even 'better' than in other children. PDD is quite different from what is called "global developmental delay" which usually refers to children whose cognitive and language development is delayed but who are social and communicative typically as typically developing children are.

The specific definitions of these terms described in this handout are from the Diagnostic and Statistical Manual, version 4 (DSM-IV), which is the latest version of the manual used by physicians, psychiatrists and psychologists for diagnoses of syndromes, disorders and illnesses that have behavioral presentations. This version of the diagnostic manual has just been published, and many people still use the previous version, version 3R (R stands for Revised), which was somewhat different. These terms are also used often by speech pathologists, teachers, and the general

public, although not everyone uses them in the same way. What these terms refer to, and their various uses, are outlined below.

Types of Pervasive Developmental Disorders:

There are currently 5 subtypes or subcategories within the overall PDD diagnostic category. These are: 1) PDD "not otherwise specified", 2) Asperger's disorder, 3) Autistic disorder, and the last 2 categories, which are very rare: 4) Childhood disintegrative disorder, and 5) Rett's disorder. Below are a few sentences on each.

The first three groups below are often loosely called "PDD", and also often loosely referred to as autism, by professionals and families. While some children are clearly best described by one term or another, for many children the distinction between these categories is not always clear, and professionals may disagree on which term which best describes a particular child. Fortunately, in terms of treatment, while it is helpful to be aware that a child has challenges associated with PDD, and to understand each child's learning profile, it is not necessary to establish complete agreement on which of the 3 categories below is most applicable. In fact, sometimes people prefer to use PDD or Asperger's or no diagnostic term at all, because

they feel it is less stigmatizing, while at other times the use of the term "autism" is most helpful in accessing appropriate services.

1) Pervasive Developmental Disorder "Not Otherwise Specified" (PDD-NOS; also called "Atypical Autism"): This is probably the most common category within PDD. PDD-NOS is generally used to mean "mild autism", or "some autistic characteristics". Often doctors will simply use the shorthand of "PDD" when referring to PDD-NOS. This term refers to children who have significant difficulties in the areas of social interaction, verbal communication (speech), nonverbal communication (gesture, eye contact), and play, but are too social to be considered fully autistic.

2) Autistic Disorder: this term refers to children who have very significant difficulty in social interaction, in language, in nonverbal communication (e.g., eye contact; gesture), in pretend play, and who have a restricted range of interests. This diagnosis is less common than PDD-NOS and applies to about 2-5 children out of every 10,000. There are several specific 'symptoms' from a list in DSM-IV related to these difficulties, that children must show in order to meet the criteria for Autistic disorder. About

75% of children with autism also have mental retardation (that is, are significantly behind age level in all areas of understanding), while 25% of children with autism have "normal" intelligence except in areas related to language, social, and play development.

Note: Some professionals and families use the terms "autism" and the term "PDD" to refer to the same set of difficulties.

3) Asperger's disorder (sometimes also called Asperger's syndrome): this diagnosis refers to children who have PDD as described above (severe difficulty in social interaction and verbal and nonverbal communication, have a narrow range of interests and repetitive behaviors) and who have **"normal" language and cognitive development**. Sometimes the term "high functioning" children with autism has been used to describe this group of children. "Raymond", the character played by Dustin Hoffman in the movie Rainman would probably have fit in to this general category. While this term has been used commonly in England, it is newly included in the DSM-IV (1993) in this country. Previously children meeting these criteria would most likely have been considered to have PDD-NOS.

The following two disorders, only recently included under the general PDD category, are extremely rare and rather different from the above categories:

4) **Rett's disorder (also called Rett's syndrome):** this is an extremely rare (much more rare than autism) medical disorder that has not previously been included within the diagnostic category of PDD. It is now included because in addition to the medical symptoms described below, children with Rett's disorder do also usually display the social, communication and play difficulties associated with PDD, at least for a period of time when they first loose skills. The physical development of children with Rett's disorder is very distinct, and includes the following: normal prenatal and perinatal period, with normal early motor development and head circumference; dramatic loss of purposeful hand skills between 5 months and 30 months; subsequent onset of hand-wringing movements; loss of many gross motor skills and onset of poor coordination; head growth slows compared to age mates. Rett's disorder has only been reported in girls.

5). **Childhood Disintegrative Disorder:** this is also an extremely rare occurrence, much more rare than autism, in which the child develops normally in all areas, and then at some point between 2 years and 10 years the child loses skills across many areas. That is, the child loses social and language skills, like many children with PDD-NOS, and also may lose motor and/or bowel and bladder control. The degree and extent of loss of skills is more pronounced than children with other forms of PDD who may also develop and lose some social and language skills.

Summary of the most common categories of Pervasive Developmental Disorders:

Asperger's Disorder

Child with diminished nonverbal communication and social interaction but normal language and cognitive development

PDD-NOS

(Not Otherwise Specified) Child with diminished nonverbal communication and social interaction and delayed language (may have typical or delayed cognitive development in other areas)

PDD-Autistic Disorder

Child with very significant difficulties in language, nonverbal communication and play (may have typical or delayed cognitive development in other areas)

12

What are general characteristics of children with PDD?

Below are examples of three "typical" children with the general diagnosis of PDD.

1. Bobby's difficulties were apparent from an early age in the social and communication areas although he developed quickly in other areas.
2. Mary showed delays in all areas, with more significant delays in social and communication areas.
3. Joey began with typical development in all areas and then seemed to withdraw, and lost social and language skills.

While there are other patterns of development for children with PDD, these three are the most common. Full evaluation would determine which term is most appropriate, although the general designation of PDD, with the child's additional cognitive and social strengths and weaknesses would provide a 'shorthand' description for each child:

Bobby, with PDD, possibly Asperger's disorder: Bobby, now 2-and-one-half years old, was born to his healthy young parents after a perfect pregnancy. He had been an "easy" baby who was content to play alone in his crib for long

periods. He had smiled and laughed at 2 months, walked at a year, always loved music, and his parents felt he was a happy baby. He seemed very smart, showing an early interest in numbers and letters, and was able to recite the alphabet, count to 20, do difficult puzzles, make great designs with his blocks, and had many tunes and some story books memorized by 2 years. He was fascinated by certain videos which he watched over and over. His parents became concerned though, around a year, that he often didn't respond when they called his name, and that while he had a large vocabulary and used some sentences, he didn't use the words to communicate the way other children did. He sometimes recited lines from his videos, or the alphabet, rather than answering a question. He didn't seem to want them to join in his play. When he wanted something he couldn't reach, instead of pointing, he would get it himself, or pull a parent's hand over to it, or might say, "You want juice?". He didn't play with other children although he sometimes watched them. He didn't make much eye contact with other children or adults although he often did with his parents. When he was very excited he sometimes danced around on tiptoes and waved his arms, shrieking loudly with happiness! It was sometimes hard to get him to behave in busy places or during transitions, like going food shopping or to other peoples' houses. He had no interest in toilet training. Sometimes he was cuddly but often he was not, and he didn't usually

look to his parents if he fell down or if he seemed to need help. When his parents sang to him, he made good eye contact. His parents were worried about his delay in speech and social interaction although they saw he was making some progress.

Mary, with PDD, probably Autistic Disorder, and probably also Mental Retardation: Mary, 3 years old, was an adorable healthy baby. Her parents had been concerned about her from the first months, as she was late to reach all the early milestones, and seemed less alert than they felt she should be. She had been in Early Intervention due to her global delays. She recently began walking and was starting to say a few words by 3 years. Her parents became concerned that Mary might also have autism, in addition to her delay, when they watched another child in her playgroup with Down syndrome, who was delayed too, but was much more social, smiling to her parents and coming to show them her 'boo boos' and her toys.

Joey, with PDD - Autistic Disorder: Joey, also 2 years old, was also a healthy adorable baby born after a healthy pregnancy, to healthy parents. He had developed ahead of the 'charts' his first year and a half in every area; he would greet his parents in the morning pulling up to stand, smiling and saying "Hi" and holding up his arms to be held by 12 months. He crawled around the house

chasing his older sister and imitating everything she did. He got a few more words after that, and then seemed to slowly withdraw, smiling less. He stopped using the words he had, made less eye contact, stopped imitating his sister and seemed difficult to reach. His parents felt they were "losing him".

Note: For the rest of this handout, we will use the broader term PDD to refer to Asperger's disorder, PDD-NOS, and Autistic Disorder, unless we specify otherwise.

What causes PDD?

The real answer is that we don't know yet. We do know that **PARENTS DO NOT CAUSE PDD.** Initially, in the 1950s, mothers were unfairly blamed for children with these difficulties, so it is important if you read older books, to know that we have since learned that parents and families do **not** cause these kinds of problems. In fact it would probably not be possible to 'make a child autistic' even if one tried!

Mothers' actions during pregnancy such as drinking or smoking do not cause PDD. Also events prior to getting pregnant do not seem related. Parents often wonder if their child's difficulties could have been caused by a fall they

had, drugs they used when they were younger, returning to work too soon after the baby was born, an unplanned pregnancy etc., (or anything else a parent can manage to feel guilty about!). Studies indicate that these factors are generally unrelated to autism and PDD. It is important to go over your child's specific neonatal and birth history with a developmental pediatrician to explore any factors you may have concerns about.

PDD is a "biological" disorder. It may be helpful to think of PDD as being a form of learning disability, in the social and communication areas. There are many studies going on examining biological and structural aspects of the brains of people with autism, and there have been some promising findings, but so far there are not clear cut answers. It may be that there are several different causes that all result in a similar set of behavioral characteristics. It is about 4 times more common in boys than in girls.

Is it ever caused by the birth of a new baby or family stress?

No. Autism or PDD are not caused by social events. Some children begin to develop normally, even get a few words, then around 1-and-one-half or 2 years of age, seem to withdraw and lose the words they had. This is a common (and, for fami-

lies, clearly devastating) progression for children with PDD or autism. PDD is often first noticed when children do not develop language around 1-and-one-half or 2 when it would be expected. New brothers and sisters are often born when children are about this age. Also grandparents are getting older and illness and death in extended family is common at this age. Mothers often return to work around this age. Parents and extended family often worry that these sorts of outside events caused the child's difficulties. Sometimes people wonder if parental arguments, divorce, or a family move could be the cause. We are quite certain, however, that the timing of these events with a child's difficulties is coincidental.

Do children with PDD have specific medical problems?

Most children with PDD or autism are physically healthy and look "normal". There are a few medical issues, however, that can be associated with PDD: many children with PDD have inconsistent responses to sound (very sensitive to some sounds, covering their ears, while seeming to be able to tune out other sounds at times). Often parents are at first concerned that their child may be deaf, and while it is very important to have an audiologist check the child's hearing, testing usually indicates normal hearing. Some children

have specific syndromes or disorders, and the autism or PDD is an additional diagnosis. Some children have mild motor problems such as a little clumsiness, while others are quite agile. Some may have sensitivities to certain kinds of touch, and may walk on their toes. In autism, there is a higher incidence of seizures in adolescence. A thorough medical work-up is very important to rule out any other difficulties.

Are all children with PDD or autism all the same?

No. There is a great deal of variety in children with these diagnoses. You may know another child with the same diagnosis who is not at all like your child and wonder why the same term would be used for both children's difficulties. First of all, children with PDD, like all children, have many aspects to their personality. Like all children, they get bits of their personality from their parents, and also have their own unique personalities. Also there is great variation amongst the children in terms of the characteristics associated with PDD or autism: Some may make lots of eye contact with their parents and may be very affectionate and cuddly with familiar people, while others may seem to be more "in their own world". Some have specific behaviors like hand-flapping or making unusual noises, and others don't. Some are hyperac-

tive and others are lethargic, or "just right" in terms of activity level. Some show unusual play in that they line up objects or spin wheels or become virtually obsessed with certain TV shows or videos, and others do not. Some want to have certain things the same way and get upset with change (e.g., want to take the same route every day; get upset if people sit in the wrong chair) and others do not. Some have severe tantrums or major sleep problems and others do not. Some are very sensitive to certain sounds and others are not. Some are picky eaters and will only eat certain foods (only eat Cheerios and Spaghettios for example) while others are not. Some are unusually advanced in certain areas, such as showing very early reading ability or exceptional memory for songs or dialogue, while others are not.

What the children have in common is significant difficulty communicating, and engaging in longer social interactions. Most do little "pretend play" as well.

How do I know if this is the correct diagnosis for my child? What if it is a mistake? What if different evaluations have resulted in different diagnoses?

If you have doubts about whether the diagnosis given fits your child, you should probably get a

second opinion. Ideally children with PDD should be evaluated by a team which includes a developmental pediatrician, a speech and language pathologist, an audiologist, and a psychologist and/or psychiatrist. A great deal of time (several hours) should be spent by the team getting to know your child well through observing and interacting with him as well as through talking with you about his development, what he is like at home and his responses to different situations.

If you have gone through a thorough diagnostic process and you still feel it may not be the right diagnosis, you might want to consider pursuing the recommendations in terms of intervention and school, for these interventions are generally helpful to all children with language problems, even if you disagree with the label. ***You do not have to use or accept any label you are not comfortable with for your child, but the interventions will most likely be beneficial.*** After getting a second opinion it may be most helpful to put the diagnostic issue aside for a year or so, and get a follow-up evaluation after a year of schooling to see what makes sense at that point, or to drop this issue altogether except where you can use a label to your child's advantage to get certain school services, for example.

Families often get conflicting advice from well meaning people; grandparents may be saying "He's fine—don't let them tell you there is anything wrong with your child", the pediatrician may be saying "Don't worry, Einstein didn't talk until he was 5". Sometimes, but not always, fathers tend to minimize problems and mothers tend to be the worriers. It is helpful to remind oneself and extended family that you don't need to all agree on what the problem is, you just have to agree on what should be done to help the child, including getting him to school. It can sometimes be helpful to bring the extended family to clinic appointments.

Again, if professionals give different specific diagnoses within this general category (e.g., one says "Asperger's"; another says "PDD"; and another says"Autism"), that could very likely be due to different uses of these terms rather than disagreement about your child's challenges and needs. While it would be helpful if everyone used these terms in the same way, the most valuable information to get from evaluations really is the recommendations regarding intervention / schooling, rather than the specific label or diagnostic category within PDD.

Are children with PDD or autism mentally retarded?

There is a wide range in the intelligence of children with PDD. Some (perhaps about 75% of children with autism) are mentally retarded, which means they function substantially below the level of their peers in almost all areas. Others have average intelligence in spite of significant social and communication deficits. All children with Asperger's disorder, by definition, have at least normal intelligence. A few children with PDD have very superior intelligence. Most have "uneven" profiles in that they may be very good in some areas (such as puzzles, mechanical tasks, letters, numbers, spatial memory, and auditory memory) and have great difficulty in other areas, especially language, communication, and abstract reasoning.

It is often difficult to evaluate the intelligence of very young children with PDD, due to social, communication and behavioral difficulties, and it may be unclear what your child's intelligence is until she gets a little older.

Does PDD run in families? Is my next child at a higher risk?

There is a higher chance of subsequent children having autism or PDD, statistically. What the

chances are in the particular case of your child and family can best be assessed by specialists in genetics. Language disorders often do tend to run in families with an autistic child. If you are planning more children you may find it helpful to consult your pediatrician and a genetic counselor to determine risk factors in your particular family.

Do children with PDD or autism learn to talk?

Most children develop some way of communicating. Many develop excellent verbal language, while others continue to have difficulties in this area. A general rule of thumb is that developing some speech before age 5 years is a "good sign" that the child will continue to develop more speech. Often at first children will begin to communicate using a variety of means including behavior, some signing, some picture communication, and some gestures. Sometimes use of computer technology can be helpful. All of these nonverbal approaches seem to help language develop.

At some point your child may begin to use "echolalic" speech, which means copying part or all of your sentences, either right after you speak, or at some later time ("delayed echolalia"). While at first this may sound unusual, it is actually a very

good sign in that children who develop this type of speech tend to then progress to more spontaneous language. This copying seems to help them learn to use language more independently, and is actually part of the process of language development for "non-PDD" children as well.

Do children with PDD recover?

Some of the children get completely better. Many clinicians in the field are describing many children with full recovery, although in the literature this is more rare. Perhaps the recent trend in earlier diagnosis and more intensive treatment is changing these statistics. All of the children continue to make progress. Most continue to have some difficulties in the areas of social and communication skills. Unfortunately we do not know enough about this disorder to predict well how far specific children will progress, or what your child will be like in the future. We do know that children who a) get intensive early schooling, b) who have good intelligence, and c) who develop speech before age five, have the best prognosis. Intervention and specialized educational resources, with carry-over between home and school, seem to be helpful to all children. As your child gets older, better prediction becomes more possible. It is important to keep in mind that people with PDD can have quality lives even if they don't have full "recovery".

Why does my child have such difficult behaviors?

Many (but not all) children with autism or PDD have difficult behaviors. These behaviors can include long tantrums for apparently small reasons, difficulty in sleeping, sometimes aggressive behavior, unwillingness to cooperate, trouble with transitions, running off, etc. Some behavior problems may be due to the social and communication problems. That is, children with PDD have difficulty understanding what is expected of them, and also have difficulty expressing their own wants and needs. This is all complicated further by their difficulty in understanding your attempts to praise/scold them. With your other children, a certain raise of your eyebrow may be enough to get them to stop doing whatever it is they shouldn't be doing, but with a child who has PDD that eyebrow raise may not have any particular meaning. That is, not only do children with these problems often have behaviors that are more difficult, it is also more difficult to teach them other ways to behave. Having difficulty managing the confusing and challenging behaviors of children with autism or PDD is really universal, and has nothing to do with how good a parent you are.

If your child has behaviors that are difficult to manage or if you are not able to go to places such as the mall or out to eat because of her, you would

likely benefit from having help from a behavior specialist familiar with positive behavior techniques that are successful with children with autism and PDD. This specialist can usually be accessed through the school system, and should come to your home to give you "on-line" lessons. Once you learn a general approach, you will be able to do this on your own without the specialist.

What type of intervention or school is best for my child?

In general, programs should have the following ingredients: structured, predictable schedule so the child can anticipate changes in the day; relatively few children per teacher; emphasis on social and communication development; use of play and child-child interactions to promote social and communication development; use of positive behavior management techniques to help with behavioral problems.

There are several different schools of thought about what educational and therapeutic approach is best for children with autism. Research involving programs with a strong behavioral component, including Applied Behavioral Analysis is quite promising, as is the research of speech and language specialists promoting communication. At this time no specific single approach seems to have

emerged as "the best" for all children with PDD. What is best for your child depends on your child's needs, and your family lifestyle and philosophy, and the accessibility of various types of programs. Often supporters of one type of program or another will make claims that theirs is the one successful approach for children with PDD or autism, and it is important to examine the program carefully and speak to other parents and professionals before making a decision.

Because many children with autism or PDD have challenging behaviors, the program should include a person who can help parents develop further skills for positive behavior management, such as a behaviorist or a behavioral psychologist. In many cases this should be someone who can come to your home once or several times a week while you develop these skills. Guidance and intervention from an Occupational Therapist and a Speech Therapist will be very helpful in terms of approaches to maximize communication. Communication amongst all those involved in working with your child is also vital so there can be some consistency in approach and goals. If the class is not specifically for children with autism or PDD, teachers should be comfortable with techniques to promote development in these children. Ideally the program should be 11-month and as close to full-day 5 days per week as possible.

Increasingly, as part of the "inclusion" movement, children with special needs are placed in regular classrooms with consultation and supports from special education teachers. When this is successful it is an exciting and powerful model, teaching all involved about acceptance of differences and providing a very normalized setting with many role models and opportunities for interaction for the child with special needs. However, some children with autism and PDD may become easily overwhelmed in a large and busy classroom, and may have difficulty sustaining attention unless tasks and activities are specifically tailored to their unique learning style. Some regular education teachers may not have the skills necessary for optimally managing challenging behaviors. "Inclusion" may be done in small phases, with inclusion in the regular classroom for times when it is successful, and more individualized structured intervention at other times. If the child will be in a regular classroom, this must be done with extensive supports to help the child make sense of and benefit from the experience, to help the other children learn how to interact well with the child, and to help the teacher understand the child.

While in the past private schooling has been necessary for children with autism or PDD, now many towns have developed excellent specialized programs, often initially getting grants to consult with the private programs and train their teachers.

It is worth first seeing what your town has to offer before pursuing a private program, as there are several advantages to the public programs: they tend to be closer, your child may meet potential neighborhood playmates, it saves money that can ideally be spent on further developing the school program, and usually there are more possibilities for mixing "regular" and special needs children. If your town does not have an appropriate program it is your right to have them pay for a specialized program.

There are also several well known private school programs in the Boston area, each quite different, including the League School, the Language and Cognitive Development Centers, the Higashi School, and the May Schools.

Are there medications that can be helpful?

Regarding medical treatment, while various medications have been studied, there is no specific drug to treat autism. However, some medications have been useful for some children to treat specific associated difficulties, such as hyperactivity, and anxiety or self-injurious behavior. Consultation with a child psychiatrist will be helpful for these issues. When considering medication it is important to discuss with the psychiatrist or pediatrician

what particular benefits it may have as well as risks or side effects. Balancing these issues will help you make a decision.

What about new treatments like "auditory training", vitamin therapy, and "facilitated communication"?

Maybe because there is not one specific proven "cure" for autism and PDD, there is a steady flow of new and often controversial treatments. These treatments are often quite costly in terms of money and time. Most new treatments are initially given a lot of publicity, often on TV and in the newspapers, and often presented as very promising. This often occurs before there have been careful studies to evaluate their effectiveness. Over time as the treatments are studied more carefully and more specific information becomes available they are often discovered either to not work at all (as it appears is likely the case with facilitated communication) or to work only with a few specific children. Sometimes it turns out that they are helpful in some form for some aspects of autism for some children. Parents are caught in a very difficult situation, for they would naturally do anything to help their child, but how can they know what treatment is really effective and what is a "hoax", or what might even be harmful to their child?

Some general pieces of advice about how to respond to new treatments:

1) Be an educated consumer. That is, a) find a set of professionals and/or parents you trust with whom you can discuss new treatments, b) get a journal such as the *Advocate*, which is put out by the Autism Society of America, in which new treatments are regularly reviewed, and c) when considering claims about new treatments find out if they have been evaluated by independent groups other than those who developed the treatment. It is especially helpful to keep in communication with a parent network to find out about what they have heard or experienced.

2) Wait until a new treatment has been around a while and is studied before investing time and money in it, to see if more definitive studies will be done. Clearly many people do not want to wait when it concerns their child, and this must be an individual decision.

3) Be especially wary of treatments that could cause harm, such as dramatic dietary changes, new medications, or giving massive vitamin doses. In these cases it is especially important to consult with your child's pediatrician.

How can I meet other parents? Where can I get more information?

There are several parent organizations at the national, state, and local level. Those that only have "autism" in the name also include parents of children with PDD, Asperger's disorder and other related disorders.

Autism Society of America (ASA)
7910 Woodmont Ave. Ste 650
Bethesda, MD 20814
800-328-8476
301-657-1881

This is a large national parent organization. When you contact them you will get a useful packet of information. By becoming a member you receive the monthly detailed newsletter, the *Advocate*.

Autism Support Center
64 Holten St
Danvers, MA 01923
800-7AUTISM or 508-777-9135

This is a state organization serving 29 communities in the metropolitan Boston area, and 63 communities to the north and west of Boston. ASC coordinates many helpful services such as parent groups and advocacy.

Additionally this center will try to track down answers to most questions related to autism that you may have.

Additionally, towns have parent groups or Parent Advisory Committee's (PACs) for parents of children with any type of special need. These groups are especially helpful in terms of organizing around accessing appropriate services.

For young children, the October 1992 *Zero to Three* journal had a very helpful and readable set of articles on intervention approaches that parents can readily adapt to carry out at home. Most Early Intervention Programs and some libraries have copies of this journal.

One helpful book, relevant to both autism and PDD, is ***Autism: A Parent's Guide***, edited by Michael Powers, published by Woodbine House, available at most libraries and some bookstores including the Boston University Bookstore. It can also be ordered by calling the publisher with a credit card at 1-800-843-7323.

A book that describes the history of Asperger's syndrome, as well as many case studies, written for professionals in the field, but really quite readable for others, is ***Autism and Asperger Syndrome*** (1991) by Uta Frith.